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Richard J. Visingardi, Ph.D., Director

October 23, 2003

TO: Area Program Directors
MRC Directors

FROM: Richard J. Visingardi, Ph.D.

SUBJECT: Community Planning for People with Developmental Disabilities Residing at the State Mental Retardation Centers

Introduction

Over the past several decades there has been comprehensive policy direction regarding individuals with developmental disabilities and movement from state institutional-based care to communities. The policy direction is clear-- people with developmental disabilities are full citizens and, like all other citizens, should be provided opportunities to be part of communities. This direction has been evident in legislative developments, the Americans with Disabilities Act as the key example. This direction has been evident in a number of court actions. This direction has been evident in finance policy incentives, opportunities of the 1915(c) waiver as a key example. This direction is evident in our own state's mandate to reduce the census of our state Mental Retardation Centers (MRCs). This direction is supported by our practice ability to create community capacity that allows us to support and serve people with more severe and complex disabilities.

Over the past several months we have met with groups of advocates, MRC leadership, Area Program (AP) representatives and providers regarding efforts to provide opportunities for consumers to move from our state operated mental retardation centers into the community. In spite of federal and state policy direction for developing community capacity and moving people with developmental disabilities out of state facilities, our "progress" is virtually non-existent.

Recently we gathered the stakeholders identified above to develop a method of community planning to move this effort forward. Fundamental to the success of state reform are the efforts that involve building communities. This includes developing community commitment and capacity for embracing citizens with disabilities. A number of these citizens currently reside in our MRCs.

The purpose of this communication is to provide guidance in the development of community-driven efforts to provide opportunities for individuals to move from the mental retardation centers into natural communities-- a community model. This process will require the local public system to assume a community leadership and planning role in generating community commitment, organizing resources and developing capacity.

The guidance provided in this correspondence is not intended to result in slowing or stopping currently planned movement of individuals from the state mental retardation centers to the community. These efforts should continue. The guidance provided here is intended to promote a more systematic and comprehensive method of achieving successful and sustained movement from state institutions-to-community.



Initiation

The first step is for the Director's of the MRCs to contact the Director's of the APs in their respective service/catchment areas to meet and initially understand the needs of the consumers that are residing at the MRCs, whose original county of residence falls within the responsibility of the AP. Because the availability of space within the MRCs, and the lines of the catchment areas have changed over the years, it may also be reasonable for the MRCs to coordinate with other APs to determine what consumers in each of the other facilities may also call the AP catchment area their "home." The key is that the AP must have a working knowledge of:

- how many consumers from their area are residing in the MRCs;
- the initial needs of each consumer; and
- the cumulative needs of the consumers as a group.

Once the AP has a complete list of persons, it is important to meet with the MRC to ascertain which consumers are able to move and who do not object to moving to the community. This initial issue of "able" to move is typically determined by professionals working with the individual. Professionals do provide skilled direction in this regard. However, sometimes individuals we determine as "able", and particularly folks identified as "not able", need to be more closely examined and, perhaps, respectfully challenged. Please note that the comments here are not intended to discount professional input-- in fact, it is highly valued. At issue here is the consideration of two very different environments (MRC and community) as well as viewing folks from different perspectives.

Often the consumers that are finally identified to move first will be named as a product of negotiation between the AP and the MRC. **Central to these considerations are the wishes of the consumers and their family/guardians.** Some consumers who are able to articulate their desire to move may require additional community development to create adequate services while some guardians/families may be opposed to any movement. It is important to start the process with those that have the highest potential for success. Successful potential is enhanced by consumer/family desires that embrace placement and a service array in the AP provider network that will support the consumer's needs in community.

In some instances, consumers/families may desire movement to the community, however the capacity to provide or arrange the types of supports and services needed may not exist. This is about our "inability" rather than an individual's disability. In these instances, movement to the community may simply require a longer term planning effort. Because the supports these individuals require to be successful in the community are more complex or intensive, we should work with all diligence to help achieve the individual's desire to move into the community.

The Olmstead lists have been used for determining movements. Both the MRC and AP should look to these lists as a starting point. However, do not use them to constrain potential considerations for moves. The goal here is to join in partnership to provide opportunities for movement from state institutions to the community. In addition, these lists are to be managed on an on-going basis. The management of the lists includes adding the next potential consumers for movement as others exit the MRCs.

The initial process of identifying the consumers and their needs will be further developed in conjunction with the community planning effort. This will include efforts of getting to know the consumers better through a range of efforts-- from direct conversations with them to formal assessments. Ultimately, a person-centered plan will be developed. his plan will include the transitional efforts that will occur in the MRC in preparation of the move as well as how the individual will be supported and served in the community.



Regional Organizing

Planning occurs on four levels:

- AP, providers, MRCs, and consumer/family
- Regional APs and MRCs
- APs and their communities
- Individual AP and MRC

The regional planning effort is intended to promote the following:

- **Selection Opportunities:** Create greater opportunities for individuals to select what community they would like to live in. Consumers have the right to live in any community they choose-- in this state or elsewhere.
- **Resource Sharing:** Allow communities to share resources across systems. This is particularly related to resources that are of low and/or rare demand.
- **Community Strengths:** Promote the emergence of unique community strengths and offerings to be considered when informing consumers of options and opportunities. For example, one of the communities in a particular region may have greater numbers of health resources. Consumers may place a greater emphasis on the value of the health resources and opt to live in these communities.
- **Economies:** Create greater economies of scale. This is not intended to detract from a consumer/family desires. There may be some systems that have so few consumers that another community may meet the satisfaction of consumer/family.
- **Competency:** Ensure that the community is competent. In the event an AP and/or their provider network does not have the competencies to support and serve these individuals, and it is unlikely to be able to become competent, other communities may be sought out. It should be noted that an unwillingness to develop competencies results in questions being raised in other areas that may require alternative actions as well.
- **Continuity and Stability:** A regional approach will also allow a look at the people working in the MRCs who could continue providing supports and services in community systems. This not only addresses the potential for maintaining continuity at the service delivery level for consumers but also helps in potentially minimizing the economic impact of communities in close proximity of the MRCs.

Community Planning

At the "30,000 foot" level, the notion of community planning is not wholly and solely related to the public and private specialty system. The AP assumes a community leadership role in pulling the community together. There is a need for gathering support and resources from the natural community. This includes bringing advocates, religious and civic leadership and other public partners into the process. The effort needs to be one that reflects the communities' desire to embrace and support these citizens. The consumers from the MRCs will come with a host of real life needs-- relationships, spirituality, as examples-- that are not satisfied with publicly sponsored supports and services. Community leaders who are champions to the cause will help mobilize natural supports in the community that will become part of the lives of folks moving into the community. In general, APs engaged in broad-based community planning efforts in the development of their Local Business Plans (LBPs).

At the more discrete level, the public and private specialty system needs to initiate planning for the consumers that have been identified. The AP must examine the availability of qualified providers in the current AP provider network to support the identified consumers' needs. For



example, a group of persons may have in common a need for adaptive housing to accommodate wheelchairs, intensive medical monitoring needs, or opportunities for meaningful community involvement. The AP begins to work with the provider network to enhance or start up services and supports that will address the needs of the consumers to be brought out of the MRCs.

This process begins with some elementary assumptions regarding community capacity related to initial need identification. As the process moves forward-- as the system becomes better acquainted with the consumers-- the planning becomes much more specific and discrete.

One of the most common pitfalls of the community network planning process is the assumption that a consumer in the community will require exactly the same services they received at the MRC-- at exactly the same cost, or higher due to the smaller scale (in comparison to the MRC).

While it may be true that a consumer who is just moving to the community initially requires similar staffing patterns, the point of a placement is not to simply duplicate the MRC in a smaller setting. The AP and providers must work together to create new service/support constructs that fit the individual needs of each consumer. For example, a consumer requiring frequent 2:1 staffing in the MRC may be able to transition from 2:1 initially to 1:1 and then to intermittent supervision in the community. The parameters for such a transition should be included in the person-centered plan with crisis contingency plans and options for alternatives. It is not appropriate to assume that the 2:1 staffing pattern could, or should, continue for the life of the consumer.

Similarly, if the cost of a specific consumer in an MRC is "X" per year, it is not necessary or accurate to assume that the consumer will require the same "X" to live in the community. Even though staffing patterns may not achieve the same economies of scale available in the MRCs, the concept of community living is to not require the same level of paid staff supports. In addition, no community placement will have the cost factors of maintaining a large state operated facility. In reality, some costs will be greater and some smaller as compared to the costs at the MRC. In addition, costs change in relationship to changes in an individual's life conditions, circumstances and situations. These changes are addressed through on-going person-centered planning efforts.

It will take several months in community planning to prepare to begin the larger movement of consumers out of the MRCs. This level of planning is not done by case managers; it is done by public policy managers. This requires the AP to be actively and constructively engaged with their community and provider leadership. While the individual consumers' person-centered plans are at the heart of the community plan, the plan does not augment the provider network of services by one consumer's needs at a time. It is an examination and a development of a system of services and supports.

Community plans typically cover multiple fiscal years. This includes considerations of consumers moving during a fiscal year (transition year) and the full fiscal year (on-going) that they are in the community.

Finance

The Community Planning Model calls for designing the process and the system first, and then attempting to determine the cost to implement the design. The initial implementation costs may also differ from the cost of sustaining the services; therefore a complete plan would include start-up, transitional costs, and estimates of the on-going costs to maintain the service system.

Start-up costs includes ensuring the necessary capacity and competency of the provider network is in place at the time of the move. As an example, this includes the recruitment, training and on-site experience of community support staff (including pre-move working with consumers at the MRC). As another example, this also includes the costs associated with staff that need to work with consumers prior to the move (visits, assessments, trips to the community necessary for identifying and securing resources.)



Transitional costs are associated with costs that may be required at the onset or during the early phase of the move but are not likely to be required long term. Typically, the costs associated with moves to the community reflect an "uncertainty"-- with the decision to make any "errors" on the "conservative side" so there is not a shortage of resources to support the consumer. In these instances, the person-centered plan reflects the conditions that need to be met in order to relieve the uncertainty. For example, staffing ratios may initially be at a particular rate that can be reduced once empirical evidence post the move has been gathered. Transitional costs also consider the portion of a year a consumer moves into the community prior to the full fiscal year.

On-going costs reflect the longer term support and service needs.

The community plan should simply identify, categorize and provide a rationale for each category of costs. Once the plan is submitted, the DMH/DD/SAS will initiate negotiations with the AP. This process will include developing the revenue plan necessary for financing the community plan.

Start-up and transitional resources for this endeavor will most likely come from the Mental Health Trust. On-going resources to sustain the community system will mostly come from the savings resulting from downsizing of the MRCs along with other funding resources that may become available as a result of the overall changes to the system. The MRC funds are non-federal net funds that become available as a result of bed reductions that are, in turn, applied as match dollars to draw down federal funds (via 1915(c) waiver services in the community, as a key example).

Initial plans for transition and community capacity development should be submitted to DMH/DD/SAS by March 1, 2004. This will allow time to complete negotiations and engage in MRC and AP finance planning for SFY 04/05 and beyond. Final community plans should be submitted to DMH/DD/SAS by no later than May 2004 and should include identification of the As this is a dynamic process, status reports and changes of community plans would occur on a quarterly basis.

Plan Submission and Updates

The format for community plans must reflect the following (for each Fiscal Year):

- **Number:** The number of consumers moving by fiscal year they move (transition year) and full fiscal year (on-going year) they are in the community. These consumers would be listed by name and facility. Movement dates are estimates that are updated quarterly as actual move dates are known.
- **Planning Process:** A brief description of the planning process and problems. This includes providing an overview of the community leaders and systems that were involved, highlighting efforts that went particularly well (what you are proud of). This also includes a brief description of how you brought your providers together, including additional provider network development efforts.
- **Community Capacity:** Identification and description of the community capacity that will be in place in conjunction with the moves that are planned. This should include the types and amount of the new supports and services. This also should include a description of what is currently in place (allows for an understanding of expansion and the evolution of comprehensive capacity).
- **Costs:** This should include identifying, describing (and providing a rationale) and categorizing costs as start-up, transitional and on-going. In addition, costs that will not require additional state support should be identified.



- **Diversification:** It is essential that the plan reflect how the system intends to diminish the need for admissions to the MRC as a result of community capacity expansion and re-organization. This, in part, relates to finance. For example, if a system is going to move 10 consumers and will have 5 admitted, the state only has the balance-- 5 beds-- to consider in financing the plan. More importantly, this relates to developing and maintaining comprehensive community capacity to best respond to the needs of people outside of the MRCs. This requires communities to develop local crisis and long term solutions as part of the support and service array.

In November, 2003 we will publish a formal template for the submissions of the plans. The content of the format will reflect the information described above.

Questions, requests for technical assistance and consultation and the submission of plans and updates should be directed to your LME Contract Management Team Liaison.

State Management Structure

The following is a description of the state management structure for supporting this endeavor:

- DMH/DD/SAS State Operated Services (three members of the central office staff as well as a representative of each MRC), Community Policy Management (all members of the LME Contract Management Team) and Resource and Regulatory Management (a representative of the Budget and Finance Team) sections will be responsible for implementing and managing this overall effort. This team will be in place within 5 days of the date of this letter. Other members of the DMH/DD/SAS, particularly the Advocacy and Customer Services Section, will be consulted on an on-going basis by this team.
- A state level work group consisting of DMH/DD/SAS (including MRC representatives), Area Program, advocacy agencies and providers will be established by the Division Director and will help work through complex issues and barriers encountered throughout this process. This group will have 8 to 12 members and will be in place within 30 days of the date of this letter.
- The newly operating Advocacy Advisory Group will be kept informed and consulted regarding the state-to-community efforts with people with developmental disabilities. This group is already in place.
- The Chief of State Operated Services and Chief of Community Policy Management are accountable to the Director to ensure this effort moves forward in a timely and appropriate manner. The Director is held ultimately accountable for this endeavor.

Next Steps

In order to move forward, the following "next steps" will occur:

- MRC Directors, in conjunction with members of the State Operated Services and the LME Contract Management Team will organize regional meetings between the MRC and AP representatives to orient folks to this overall effort. These meetings are to be completed within 15 days of the date of this letter.
- LME Contract Management Team Liaisons will contact each AP within 30 days of the date of this letter to initiate the process of monitoring developments and establishing the problem solving process.
- State Operated Services central office members will contact each MRC Director within 30 days of the date of this letter to initiate the process of monitoring developments and establishing the problem solving process.



- MRC representatives and AP representatives should work together to develop the lists of consumers within 45 days of the date of this letter. The MRC Directors are to contact the AP Directors to initiate this process.
- APs will initiate their regional and community planning efforts within 60 days of the date of this letter.

Closing

The state statutory requirement regarding the downsizing of the MRCs is 4% per year. Taking into consideration this 4% factor, the number of consumers currently in the MRCs and the number of APs, assuming all is equal, this represents only 2 or 3 consumers per AP per year. Given the amount of time and energy in community planning and the need to achieve some economies of scale-- at the MRCs and in the community, this is not a very efficient target. With full consideration to the desires of consumers and families, we should challenge ourselves well beyond the 4% statutory expectation. This requires exemplary leadership and concerted and dedicated efforts. I have confidence that we can achieve the goals that lie before us.

I appreciate your leadership efforts in building communities that embrace people with developmental disabilities as full citizens.

RJV/lh

cc: Secretary Carmen Hooker-Odom
 Deputy Secretary Lanier Cansler
 Assistant Secretary James Bernstein
 DMH/DD/SAS Executive Leadership Team
 DMH/DD/SAS Advocacy Advisory Group Members
 Carol Duncan-Clayton, NC Council
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 Mike Mayer, NC Providers Council
 Peyton Maynard, DDFA
 Jill Keel, Autism Society
 Connie Cochran, UCP
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